DOCUMENT RESUME

ED 354 701 EC 301 886

TITLE	Siblings: Brothers and Sisters of People Who Have Mental Retardation. Arc Q & A Series.
INSTITUTION	Arc, Arlington, TX.
SPONS AGENCY	Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul.
PUB DATE	Jan 93
CONTRACT	MGPCDD-25200
NOTE	3p.
AVAILABLE FROM	The Arc, 500 E. Border St., Suite 300, Arlington, TX 76010.
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Child Rearing; *Disabilities; *Emotional Adjustment; *Family Relationship; *Mental Retardation; *Sibling Relationship; *Siblings

ABSTRACT

Basic information about siblings of people with mental retardation is presented in a question-and-answer format. The following questions are addressed: "Is having a sibling with a disability different than having a sibling who does not have a disability?"; "What are some of the concerns of siblings of people with disabilities?"; "Are there any benefits to being the brother or sister of a person with a disability?"; "What are some positive actions parents can take with their children when there is a sibling with a disability?"; "How does family structure affect siblings?"; and "What is being done to address concerns that siblings may have about having a brother or sister with a disability?" Also provided is a list of three organizational resources and five references. (DB)

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The Arc

a national organization on mental retardation

Q&A

SIBLINGS: BROTHERS AND SISTERS OF PEOPLE WHO HAVE MENTAL RETARDATION

Is having a sibling with a disability different than having a sibling who does not have a disability?

Yes and no. The relationship between siblings can be a very important part of any person's life. Siblings often share the same family experiences and form a special relationship which can last throughout their lives.

Children who grow up together in the same family can form a unique bond, regardless of a brother or sister having a disability. In fact, the relationship between siblings and their brother or sister with a disability can be identical to the relationship between any brother or sister. They may be close and remain so into adulthood, or they may never develop a close relationship or grow apart as they get older. Family situations and circumstances, such as divorce or even cultural differences, can also affect the way a sibling relationship develops.

It's important to remember that a lot of factors affect how siblings relate to each other, and not just the fact that one of them has a disability. However, sometimes having a brother or sister with a disability in the family creates challenges that other families may not experience. Some of these challenges can directly affect the siblings.

What are some of the concerns of siblings of people with disabilities?

In any family, good or unfavorable feelings may develop between siblings or because of siblings. This is true in both families with and without a family member with a disability. But many siblings who have a brother or sister with a disability have reported concerns surrounding having a brother or sister with a disability. Valdivieso, Ripley and Ambler (1988) discuss these concerns which include:

- Guilt about not having a disability, while the brother or sister does have one. Some siblings may even feel they are to blame for their brother's or sister's disability.
- Embarrassment of the sibling's behavior or appearance. The sibling who does not have a disability may avoid contact with the brother or sister, not invite friends to the home, etc.
- Fear that they might develop the disability. Children (and sometimes even adults) think that disabilities such as mental retardation are contagious.
- Anger or jealousy over the amount of attention the brother or sister with a disability receives, especially if the child's disability requires additional care.
- Isolation or feeling like no one else has the same feelings or experiences about having a sibling with a disability.
- Pressure to achieve in order to "make up for" a brother or sister's inabilities. The sibling who does not have a disability may feel that excelling in school, sports or other ways will compensate for the fact that a brother or sister with a disability is not able to do as well.
- Caregiving, especially if it conflicts with plans with friends or the responsibility becomes overly burdensome.
- Information needed about a brother or sister's disability. Siblings often are not given thorough information about why a sibling has a disability, how it affects him or her and what the family can do to help this family member.

Many of these feelings affect children as they are growing up, but siblings often continue to have concerns even as adults. For example, siblings who do not have a disability may be concerned about the future of their sibling with a disability after the parents die, especially if this brother or sister still lives at home.

Are there any benefits to being the brother or sister of a person with a disability?

Yes. Research on siblings indicates that there are positive aspects in being the sibling of a brother or sister with a disability. Researchers have found that children in families where a sibling has a disability can become more mature, responsible, self-confident, independent and patient. These siblings can also become

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more altruistic (charitable), more sensitive to humanitarian efforts and have a greater sense of closeness to family (Lobato, 1990; Powell, 1993).

Growing up with a sibling who has a disability may instill a greater level of understanding and development in the siblings who are not disabled. They may develop greater leadership skills, especially in areas where understanding and sensitivity to human awareness issues are important. Many leaders in The Arc and other contributors to the field of mental retardation, as well as other notable people, grew up in families with a brother or sister with a disability.

What are some positive actions parents can take with their children when there is a sibling with a disability?

Itzkowitz (1991) discusses some positive actions parents can take with their children, including:

- Treat the child who does not have a disability as a child, not just as another adult caretaker. Do not demand or expect a child to take on responsibilities for which he or she is unprepared.

- Remember that children have feelings too. Take time to ask them how they feel about having a sibling with a disability. Encourage them to express their feelings openly.

- Provide siblings with choices and include them in decision-making. Discuss family matters with your children, especially if it affects them personally. Ask for and value their opinions.

- Give them information about their brother or sister's disability. Answer their questions and respond to their concerns in a simple but precise manner.

How does family structure affect siblings?

Some studies have looked at gender and birth order to see if either one has an affect. In most situations, these factors may make only a slight difference, except in the case of increased caregiving responsibility. Research has shown that older daughters who do not have a disability are typically expected to provide more caregiving to a brother or sister with a disability. (Lobato, 1990).

What is being done to address concerns that siblings may have about having a brother or sister with a disability?

Many chapters of The Arc and other organizations are focusing services and sibling support groups aimed at meeting the needs and concerns of young children, teen-agers and adult siblings of people with disabilities. Sibling groups provide a forum where siblings can discuss their experiences, share ideas and give each other support. Other sibling services include seminars and meetings that address topics of interest to siblings such as futures planning (guardianship, alternative living arrangements, etc). Programs which provide family supports, such as respite care, are also including the siblings in the planning process or by providing services in integrated settings where all siblings can participate.

For further information on siblings and family supports, contact:
The Arc's Family Support Project, P.O. Box 1047, Arlington, TX 76004. Local - (817) 261-6003. Toll-free voice - 1-800-433-5255. Toll-free TTY - call 1-800-855-1155 and ask the operator to call collect (817) 277-0553.

Other information sources:
Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way NE, Seattle, WA 98105. (206) 368-4911.

Sibling Information Network, The A.J. Pappanikou Center, 991 Main Street, East Hartford, CT 06108. (203) 282-7050.

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Special thanks to Donald J. Meyer, Director of the Sibling Support Project, Children's Hospital and Medical Center, Seattle, Washington, for his assistance in preparing this *Q&A*.

Publication of this Q&A was supported in part by Contract Number 25200 under provisions of the Developmental Disabilities Act of 1991 (P.L. 101-496) from the Minnesota Department of Administration, Governor's Planning Council on Developmental Disabilities. The views expressed herein do not necessarily reflect the position or policy of the Governor's Planning Council on Developmental Disabilities nor that of the Minnesota Department of Administration.

January 1993